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Risk Management: a personal perspective

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King's College London

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A photograph of two white dice resting on a green lawn. The dice are positioned diagonally, with one in the foreground and one slightly behind it. The dice are white with black pips. The background is a soft-focus green lawn.

Risk management

A personal perspective

Leone Ridsdale offers a personal perspective on the introduction of electronic medical records and their use in preventive care. She outlines the possibility of using this approach to identify risks for avoidable deaths in epilepsy — and reduce them





Many years ago, I qualified as a neurologist in Montreal. When I moved to the UK, I initially found my specialist qualifications were not recognised. I trained as a GP and did a weekly neurology clinic at my local district hospital. There, I saw patients newly referred from my colleagues in general practice and some follow-ups.

Most patients waited about six months for a new referral, and another six months for investigations and a follow-up appointment. The hospital provided only two half-day neurology clinics, so many patients referred for loss of consciousness/epilepsy and headache/migraine were

Tudor Hart proposed that the people with greater needs for healthcare may be less likely to access it

seen by general physicians. Investigations included a technetium scan and an EEG. I had trained in a university hospital with a computer scanner. Neither of the above tests gave me much confidence that we could exclude important pathology like a brain tumour.

Things have improved a lot since then. The numbers of neurologists

have increased more than three-fold. Most district hospitals have sophisticated magnetic resonance imaging (MRI). However, it seems to me that more could still be done to help people with long-term conditions in the community.

When I entered primary care it was just beginning to change, shifting from a demand-led, reactive service to one that was working in teams to provide preventive services and manage long-term conditions. Ideas were promulgated by the Royal College of General Practitioners and by visionary clinician-researchers, such as Julian Tudor Hart. This inspired GP made famous an idea he called the Inverse Care Law (Tudor Hart, 1971).

Tudor Hart proposed that the people with greater needs for healthcare may be less likely to access it. In poor countries or market-driven health services, this may be because those in need cannot pay for services. In the NHS, it may be because individuals do not know they would benefit from particular services, so they do not come forward to ask for them.

An early example I found in general practice was cervical cancer, which – in England and Wales in 1980 – caused over 2,000 deaths each year. If women came and asked their GP for a cervical screening test (then known as a ‘smear’ test), it would be provided.

These women would then be recalled at given intervals for repeat tests. However, many women – particularly those with a lower level of education – did not know that they could (and should) be screened. As a result, these

Risk management is now a common idea and practice. GPs have grown increasingly expert at managing risk

people were more likely to die from the disease.

In an attempt to combat this, GPs (including myself) began to offer screening to women, initially aged 36-60 (Ridsdale, 1987). The Department of Health, with Edwina Currie as a Health Minister, subsequently launched a national programme of cervical screening, and now, deaths from cervical cancer have decreased by over half (NHS, 2013).

Being proactive

Risk management is now a common idea and practice. Even banks do it. GPs have grown increasingly expert at managing risk.

The introduction of computers and computer software has been important in enabling GPs to record detailed information about all their



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registered patients. In turn, this information allowed them to target the offer of specific services to appropriate groups – including those who do not come forward so readily. Targeting of services might be on the basis of gender in the case of cervical screening, age in the case of immunisation, or disease risk factors – for example, those with obesity and raised cholesterol – who are at risk of

cardiovascular disease.

The additional work required to catalogue information about registered patients and deliver targeted preventive initiatives required the recruitment of increasing numbers of team members. These included managers, nurses and IT staff. Funding and remuneration for meeting targets was linked to practices producing data about the numbers and percentages of registered patients who had received primary and secondary preventive services. This was associated with better NHS outcomes, like decreasing deaths from heart disease and cancer (Dzeshka et al, 2015, Hamilton et al, 2013).

After our practice nurses led on cervical cancer screening, the local

Information translated into knowledge seems important to the self-management of long-term conditions

commissioners offered a group, including myself, some additional funding to audit epilepsy services. We decided it would be constructive to see if a nurse might invite everyone registered with epilepsy for advice on epilepsy self-management. The nurse had worked in the community as a health visitor and district nurse, and had some added training in epilepsy.

We found that the response was good. The sessions allowed practices to create a structured record of the information that patients had been provided on topics like driving, alcohol intake and preventing accidents (Ridsdale et al, 1997). During the 1990s, many nurse-led, condition-specific clinics were set up, financially supported by the NHS. This helped to pay for the staff required. However,

epilepsy advice and monitoring was not reimbursed.

Information translated into knowledge seems important to the effective self-management of long-term conditions. We therefore asked people with epilepsy who were registered with our local practices to complete epilepsy knowledge questionnaires. As a result, we learned more about their knowledge of epilepsy. Our patients had experienced their condition for over 20 years (on average), but their knowledge of epilepsy varied a lot.

Those who had been at school longer, who had more qualifications and who belonged to self-help groups had more epilepsy-specific knowledge (Ridsdale et al, 1999a). It seemed as though the inverse care law also applied in epilepsy. It was another example of Tudor Hart's Inverse Care Law. If knowledge of a condition is important in self-management, it is likely that those who have less of it will experience more negative impact on the quality of their lives (Ridsdale, 2009).

It is difficult to show a change in knowledge when people have experienced a condition for many years. That said, knowing that people with epilepsy were satisfied with additional information provided by a nurse was encouraging (Ridsdale et al, 1999b).

We wondered if specialist nurses providing education on self-care might be most helpful after epilepsy was first diagnosed. We found that it was particularly the quarter of people who beforehand knew least about epilepsy that most improved their knowledge of the condition after step-up care with a specialist nurse (Ridsdale et al, 2000).

It seems likely to me that the growing number of nurses with an interest in epilepsy will improve



opportunities, particularly for people who know less about the condition to learn self-management skills within the context of their lives. This role is rather similar to the educational role played by a health visitor for young mothers, responsible for a family.

Epilepsy in QOF

I was delighted when the late Helen Lester asked me to contribute as chair

I learned from our earlier research that the cost of not offering proactive care for people with epilepsy was high

to reviewing evidence for the inclusion of epilepsy-specific indicators in the Quality and Outcomes Framework (QOF). The addition of only a few points for epilepsy seemed appropriate at first, primarily to fund a register of patients with epilepsy and their monitoring.

I believe that a similar framework for services might be provided as it is for people with diabetes, in which a set tariff rewards the delivery of a bundle of services. As part of QOF, newly diagnosed patients with diabetes are referred for a structured education programme. In diabetes, nurse specialists also visit practices, and directly advise GPs and patients with more complex problems. I hope that we can learn from this, and ask that these sorts of structured services are funded for epilepsy. Increased capacity and better training will enable us to provide step-up services in the community.

By comparison to randomised trials, testing the effectiveness of drugs, testing what are sometimes called complex interventions – by which we usually mean specific, standardised

innovations in services – is difficult. In addition, such randomised trials of say a nurse specialist service are not so amply funded as pharmaceutical research. Nevertheless, I learned from our earlier research in the community that the cost of not offering proactive care for people with epilepsy was high.

Not only is attending an emergency department for an epileptic seizure upsetting for the individual, their families and friends, it is also costly for the NHS. With colleagues, I was later able to describe why people with epilepsy come to emergency departments and exactly what the cost is (Noble et al, 2014, Ridsdale et al, 2012). When people with epilepsy experience seizures that are witnessed by family members or others, it is understandable that they worry about the risk of death. This is arguably made worse by the fact that their actual risks are often not explained to them. Where it has been explored, the evidence is that people with epilepsy do want to know their risks of sudden death (Tonberg et al, 2015). People with epilepsy who are more highly educated are more likely to know about this risk (Kroner et al, 2014), another example of inequalities affecting peoples' knowledge of health and health risk (Tudor Hart, 1971).

People want to know about their epilepsy risks too, despite unequal access to this information

I was encouraged by the success of risk identification programmes for cancer and cardiovascular disease. I was similarly encouraged by emerging evidence that people want to know about their epilepsy risks too, despite unequal access to this information. The



addition of epilepsy to QOF and the availability of GP electronic records (which provide a database representative of the UK population) stimulated my colleagues and I to undertake an analysis. We analysed anonymised GP records of people with epilepsy between 1993 and 2007 (Ridsdale et al, 2011). Research subjects included anyone diagnosed with epilepsy and then prescribed





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anti-epileptic medication. 'Cases' were defined as people with epilepsy who died from all causes. Cases were compared to 'controls', who were defined as people with epilepsy still alive at the end of the study period.

We found that deaths from all causes in people with epilepsy actually rose between 1993 and 2005 – at a time when mortality from all causes in the general population were in decline. We compared the group of patients with epilepsy who had died to patients who had not died during the study period. Patients who had alcohol problems were at almost three-fold increased risk of premature death. Risk in patients who had not collected their most recent anticonvulsant prescription for between 90 and 182 days was nearly doubled. Having 'a history of injury' during the previous year increased the risk by 40 per cent. Having been treated for depression increased the risk by about the same amount. Patients who had been seizure-free in the previous 12 months had a 22 per cent reduced risk of dying.

In a recent *BMJ* editorial, I outlined what might be done in general practice in the future (Ridsdale, 2015). This was endorsed in a letter to the editor from Philip Smith, on behalf of the Association of British Neurology. The model includes developing

We found that deaths from all causes in people with epilepsy actually rose between 1993 and 2005

risk-assessment tools for epilepsy, just as has been done for cardio-vascular disease and cancer (Dzeshka et al, 2015, Hamilton et al, 2013). If GPs have a funded programme to perform

risk assessment, there is much that might be offered to improve services and potentially reduce deaths. For example, medication adherence is something that can be monitored and discussed with patients at review.

We are currently testing self-management workshops for people with epilepsy with persistent seizures

Smithson et al (2013) demonstrated that GPs can identify people who have not adhered to epilepsy medication and discuss this with them. A court in Scotland has argued that pharmacists and GPs should be involved in monitoring the uptake of anticonvulsant medications, and in explaining why this is important (Judiciary of Scotland, 2011). This could be rewarded by QOF.

Incremental change

Sometimes I ask myself: why is so little social or press space given to epilepsy? We are currently testing self-management workshops for people with epilepsy who attend hospital clinics with persistent seizures (Kralj-Hans et al, 2014). I have attended and taught some of them. We teach that up to one per cent of the population have epilepsy. At first I was surprised that most participants say that before coming they had either met no one or only one person with epilepsy. Then they add, laughing, that they have now met 10! Many people with epilepsy are barely aware of each other; it seems unsurprising that public and policymakers are barely aware of them. Why is this?

Scambler and Hopkins described how people with epilepsy report experiencing what they described as

'felt' and 'enacted' stigma (Scambler and Hopkins, 1986). [Felt stigma is an internalised sense of shame and the expectation of enacted stigma, while enacted stigma is a more concrete experience of unfair treatment.] To a certain extent this still holds. We notice stigma is particularly challenging for people from some ethnic cultures (Sonecha et al, 2014). The perception of stigma reduces people's willingness to talk, making them less socially visible and less supported in learning to manage and cope. It also means that society is less aware of them, and policymakers spend less on epilepsy research than its prevalence and impact warrants (Gross et al, 1999). Arguably, if 'felt' stigma results in social invisibility, one consequence is that society 'enacts' stigma by allocating less resources for services for people with epilepsy.

The government estimates it spends £175 million per annum on the identification of those at risk from cervical cancer in primary care,

Stigma reduces people's willingness to talk, making them less socially visible and less supported

referral for monitoring to secondary care, and surgical intervention (NHS, 2013). Year-on-year expenditure to provide the necessary capacity and framework has resulted in the development of an excellent programme, which has more than halved the number of deaths from cervical cancer.

In 2013, total deaths in epilepsy – excluding *status epilepticus* – were 967 in England and Wales (Office of National Statistics, 2014). They outnumber deaths from cervical

cancer. In the same year, sudden unexpected deaths in epilepsy were estimated to be 2,750 in the United States, with just under 4,000 deaths in Europe (Thurman et al, 2014). These people are often young, meaning that more years of life are lost in these cases than with any other neurological condition, except stroke (Thurman et al, 2014). It will be helpful to model the estimated cost of these years of life lost.

Organisations like Epilepsy Action and SUDEP Action are to be congratulated on their passion to create space for epilepsy in the mind

of society. That space should be proportionate to the frequency of epilepsy and its impact on lives. Its creation is prerequisite to government funding that will support better research and services. Change always seems slow to those who feel passionately – but slow change is change nonetheless. I believe that there is much still to be done that can improve self-management for people with epilepsy – and general practice is a good place to start.

Papers cited by the author are directly available at researchgate.net/profile/Leone_Ridsdale/publications

Further reading

- Dzeshka MS, Gill PS and Lip GY (2015). 'Cardiovascular risk prediction: balancing complexity against simple practicality'. *British Journal of General Practice* (Vol 65, Issue 630) pp. 4–5
- Gross CP, Anderson GF and Powe NR (1999). 'The relation between funding by the National Institutes of Health and the burden of disease'. *New England Journal of Medicine* (Vol 340, Issue 24) pp. 1,881–7
- Hamilton W et al (2013). 'Evaluation of risk assessment tools for suspected cancer in general practice: a cohort study'. *British Journal of General Practice* (Vol 63, Issue 606) pp. e30–e36
- Judiciary of Scotland (2011). 'Fatal Accident Inquiry into the deaths of Erin Casey and Christina Fiorre Ilia'. In: *Judiciary* (ed)
- Kralj-Hans I et al (2014). 'Self-Management education for adults with poorly controlled epilepsy (SMILE (UK)): a randomised controlled trial protocol'. *BMC Neurology* (Vol 14, Issue 69)
- Kroner BL et al (2014). 'Characteristics of epilepsy patients and caregivers who either have or have not heard of SUDEP'. *Epilepsia*, (Vol 55, Issue 10) pp. 1,486–94.
- NHS (2013). 'About cervical screening'. Available at: cancerscreening.nhs.uk/cervical/about-cervical-screening.html [Accessed 5 Nov 2014]
- Noble AJ et al (2014). 'Clinical and Cost-Effectiveness of a Nurse Led Self-Management Intervention to Reduce Emergency Visits by People with Epilepsy'. *PloS one* (Vol 9, Issue 3) e90789
- Office of National Statistics (2014). Death Registrations Summary Statistics, England and Wales 2013. In: *Authority*, US (ed)
- Ridsdale L (1987). 'Cervical screening in general practice: call and recall'. *British Journal of General Practice* (37) pp. 257–9
- Ridsdale L (2009). 'The social causes of inequality in epilepsy and developing a rehabilitation strategy: A U.K.-based analysis'. *Epilepsia*, 10, 2175–2179.
- Ridsdale L (2015). 'Avoiding premature death in epilepsy: where do we start?' *British Medical Journal* 350 h718
- Ridsdale L et al (2011). 'Epilepsy mortality and risk factors for death in epilepsy: a population-based study'. *British Journal of General Practice* (Vol 61, Issue 568) pp. e271–8
- Ridsdale L, Kwan I and Cryer C (1999a). 'The effect of a special nurse on patients' knowledge of epilepsy and their emotional state. Epilepsy Evaluation Care Group'. *British Journal of General Practice* (Vol 49, Issue 441) pp. 285–9
- Ridsdale L, Kwan I, Cryer C and the Epilepsy Care Evaluation Group (2000). 'Newly diagnosed epilepsy: Can nurse specialists help? A randomized controlled trial'. *Epilepsia* (Vol 41, Issue 8) pp. 1,014–9
- Ridsdale L, Morgan M and O'Connor C (1999b). 'Promoting self-care in epilepsy: the views of patients on the advice they had received from specialists, family doctors and an epilepsy nurse'. *Patient Education and Counseling* (Vol 37, Issue 1) pp. 43–7
- Ridsdale L et al (1997). 'Feasibility and effects of nurse run clinics for patients with epilepsy in general practice: randomised controlled trial. Epilepsy Care Evaluation Group'. *BMJ* 314 pp. 120–2
- Ridsdale L et al (2012). 'Explanations given by people with epilepsy for using emergency medical services: a qualitative study'. *Epilepsy & Behavior* (Vol 25, Issue 4) pp. 529–33
- Scambler G and Hopkins A (1986). 'Becoming epileptic: coming to terms with stigma'. *Sociology of Health & Illness* (Vol 8, Issue 1) 26–43
- Smithson WH et al (2013). 'Adherence to medicines and self-management of epilepsy: a community-based study'. *Epilepsy & Behavior*, (Vol 26, Issue 1) pp. 109–13
- Sonecha S et al (2014). 'Perceptions and experiences of epilepsy among patients from black ethnic groups in South London'. *Primary health care research & development* pp. 1–11
- Thurman DJ, Hesdorffer DC and French JA (2014). 'Sudden unexpected death in epilepsy: Assessing the public health burden'. *Epilepsia* (Vol 55, Issue 10) pp. 1,479–85
- Tonberg A et al (2015). 'A qualitative study of the reactions of young adults with epilepsy to SUDEP disclosure, perceptions of risks, views on the timing of disclosure, and behavioural change'. *Epilepsy & Behavior*, (Vol 42) pp. 98–106
- Tudor Hart J (1971). The inverse care law. *The Lancet*, (Vol 297, Issue 7696) pp. 405–12